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ABSTRACT

The paper discusses a national project which studied 41 families who viewed the presence of their disabled child as having had a positive impact upon the family unit. Parents were asked to identify the degree of influence on adjustment of a number of variables (including awareness and understanding of the child's condition, secure economic resources, ongoing extended family support, and birth order of the disabled child). Responses were compared to responses of 17 social work departments at University Affiliated Programs. Professionals' responses reflected more uncertainty or diverse opinion than parents' responses. There was a high level of agreement between professionals and parents on those variables viewed as having the greatest amount of impact on family adjustment, including early diagnostic information, opportunity to share the experience with others, existence of more than one child in the family unit, and personal faith and religion. Twenty-four references are included. (CL)

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A COMPARATIVE STUDY OF FAMILY AND PROFESSIONAL
VIEWS OF THE FACTORS AFFECTING POSITIVE
FAMILY ADAPTATION TO A DISABLED CHILD
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ABSTRACT

When a family has a disabled member, many reactions and adjustments occur. Why do some families view this experience as one which strengthens the family unit and others do not? What factors appear to influence the reactions of the family, and how can professionals facilitate a positive adjustment to this experience?

This paper discusses a national project which studied families with a disabled child who viewed the presence of their disabled child as having had a positive impact upon the family unit. The parents were asked to identify the degree of influence a number of variables had upon their adjustment. These responses were compared to the responses of professionals who also rated the variables. These factors are presented and the ratings discussed, especially in relation to the implications the findings have for professionals working with families who have a disabled child.

It is estimated that there are forty-five million families in the U.S. who have a member with a disability. Of these, at least 750,000 are children in need of remedial or therapeutic services. Since the 1950's it has been consistently demonstrated that most disabled individuals are capable of growth, development and learning. Advanced medical technology has enabled more infants and children to survive and develop physically. The assessment and diagnostic skills of the various professional disciplines have been refined and developed to levels of sophistication so that with the evaluation of a child's capacities it is now possible to provide an individualized intervention plan that promotes the child's development. Many of the resources providing these services are in community-based programs or educational settings that aim to "normalize" and "mainstream" the child into society rather than directing him into the institutional alternative that had been traditionally provided. The majority of these current programs and services are developed around the basic assumption that the child will reside within a family unit. Parent participation in developing "individualized educational plans" and their activity in various advocacy roles has increased public awareness of these children's and families' needs.

Current social legislation now makes support services economically accessible to all families. The Education for all Handicapped Children Act of 1975, L.B. 92-194 and Nebraska Law L.B. 889, now mandate that special services be provided to children with special

needs. The increased interface that the various professional disciplines have in working with the child and the family requires each to have acute sensitivity and skills in communication to enable a viable comprehensive service plan to be established.

Considerably more social and professional attention have been given to enhance the quality of life for the family with a disabled child. The Joint Commission on the Mental Health of Children stated, "Any commitment to children is a commitment to the family unit... We must not lose sight of the fact that any service, or lack of service, which affects one member of the family affects all members, brothers and sisters as well as parents."¹ Professionals serving these families have found that mothers and fathers often undergo significant stress when parenting a disabled child (Cummings, Bailey, Rie, 1966, Cummings, 1976). Additionally, Adams (1966) stated that the family with the burden of a disabled child was, "ipso facto", a family at social and psychological risk. David and Donovan's (1976) research concluded that a physical handicap itself contributes challenge both for the child and the family.

Families with a disabled member are more likely to experience problems with individual and marital adjustment, child rearing practices, and sibling relationships than other families. Often the family is affected socially, economically, and emotionally. Waisbren found "parents of developmentally disabled children evaluated themselves as having changed in more negative ways since

the baby's birth than did parents of non-handicapped children." They reported changes in their marriage - more intense feelings of intimacy, as well as more tension, and expressed feelings about their child that suggested hopelessness, anger, or rejection (Waisbren, 1970).²

Many researchers have focused their studies on the family unit to better understand the disabled member and the interaction with other family members. Some of the earliest studies examined the impact from a psychoanalytic view which studied the "unconscious meaning" of the child's disability to a parent (Mahoney, 1958, Herish, 1961, Cohen, 1962, Olshansky, 1962, Goodman, 1964). During this time, Solnit and Stack (1961) introduced "stage theories". These and other such theories identified the sequential process families experience in coping with or adjusting to a disabled child. During the 1970's, others followed to add to these beliefs. Howell (1973), Klinger (1975), and Sieffort (1978) described the unique stages they found families experiencing. The stage theories basically focused on the "negative" aspects and coping processes which progressed from mourning toward a final stage of "acceptance" or "recovery". Subsequent to the stage theory concepts MacKeith (1973) and others argued that the processes were not necessarily stages but rather there was a gamut of reactions which could occur, reoccur, or be expressed in a variety of ways, not necessarily stages. Roos (1978), for example, identified loss of self-esteem, shame, ambivalence, depression, self-sacrifice, and defensiveness as

some of the likely responses. MacKeith (1970) described his six basic responses as protection or revulsion, inadequacy for reproduction and child rearing, bereavement (anger, grief, and adjustment) shock, guilt, and embarrassment.

Mandelbaum (1966) and others observed in the 1960's that such parent reactions should be considered as a normal process for parents of a disabled child, given their situation. The emphasis shifted then from abnormal and psychoanalytic constructs to the realistic situational stresses of the event. New theoretical hypotheses supported parent reactions as crisis-oriented in nature. Farber discussed the "tragic crisis" in his work (1960) and Wolfensberger and Menolascino (1970) identified three crisis responses, the "novelty shock", "crisis of personal values", and "reality crisis". Schild (1971) wrote of a "deviancy crisis". Sieffert expressed many professionals' views when he wrote, "It is the view that parent's initial reactions to a mentally retarded child constitute a normal coping process - normal in the sense of common and expected rather than deviant or pathological, coping in the sense of being purposeful, goal-directed, and a problem-solving process".³

There have been only a few studies which identify the positive experiences a disabled member can generate within a family. Holt's (1958) study of British families found some families experienced clearer and stronger spiritual and ethical values. Justin (1971) found little difference between parents of non-handicapped children and those with a handicapped child when he asked each to identify their major concerns.

Dunlap's (1976) recent findings differed from those of other researchers. The overwhelming majority of the parents he interviewed did not perceive the developmentally disabled person to have significantly affected family relationships and activities.

The confusion over the incidence of divorce among parents with a disabled child is well documented. Of eleven studies, two found it higher, four showed it to be lower, and five found it to be the same when compared with families without a disabled member.⁴ The diversity of such findings illustrates the lack of knowledge and concise information now available on these families and the need for further study and understanding. This project was designed to gather information from parents with a disabled child and the professionals who work with these families with the objective of better identifying the prospective positive qualities each believed could occur within the family unit and those services which would support their occurrence.

PURPOSE OF THE STUDY

This study was designed to better identify some of those factors and the perceived degree of influence each has upon a family in the positive adjustment to a disabled child. Written information was obtained from parents and professional social workers who were providing services to families with a disabled child. A comparative analysis of the responses sought to identify common and diverse views between the two populations.

This project was originally developed to study in a more precise way those variables which were noted from clinical

observations and other research. Specifically, the clinical observations of families found differences in reactions and adjustment to the disabled child. Some families expressed difficulty with coping and remorse, and required considerable supportive services and interventions. Other families developed positive attitudes and ascribed meaningful beliefs and attributes to these similar experiences. Many expressed a belief that their experiences with their disabled child had actually strengthened and enriched the family bonds. This study considered some of the personal characteristics, economic and sociological variables, family structures found by the observations, and elements identified as relevant in others' research as potential significant factors in strengthening the family's life from their common experiences with a disabled child.

The data obtained provided relevant information in at least three ways: 1) the results provide a better understanding of those factors viewed by parents as most and least helpful in assisting a family to adjust positively to a disabled child, 2) the data identified those resources and services which the parents viewed as most beneficial to them and which can possibly now be better developed for strengthening other families, 3) the similarities and differences of the parent and professionals' views when compared identify some of the conceptual and experiential differences present, and identify possible areas of communication and resource breakdown. Areas for further study were found.

METHODOLOGY

This survey was planned to gather some generic information from a sample of parents and professionals which would provide assistance in identifying relevant areas to consider in working with families, especially in intake processes, evaluation and referral for resources, and the development of community support services. The data would enable a more empirical study to be developed for further studying those variables found to have a positive impact on families with a disabled child.

DESIGN AND INSTRUMENTATION

A questionnaire had to be developed by the researchers. Information from previous studies and clinical observations and self-reports of parents interviewed were used as references. Thirty-five variables were selected to be included. The Likert scale was used for respondents to rank each variable from one to seven to indicate ranges from "little or no significance" to a "high degree of significance". For example, a rank of seven indicated the variable was perceived as having a highly significant impact on the family in strengthening the family's ability to adjust positively to a disabled child. The questionnaire was presented in three parts. First, basic identifying information of a facility was requested, second, the variables were presented, and last, a page for reflection, comment and clarification of responses was provided. Parents were not asked to provide identifying information in order to protect confidentiality, and each received only the last two sections. The questionnaire was pre-tested

with five parents to determine reliability of the stated questions. It was also reviewed by four professionals for content and other validity factors.

The mailed questionnaire was selected as a viable research tool as it enabled the researchers to include the total population of Social Work Departments in University Affiliated Facilities across the nation. It was sent to all of these facilities as well as the sample of parents at the same time and enabled relatively timely responses within a four week period. Those responding could comment candidly and impersonally and were not biased or influenced by the researchers. The questionnaires enabled the project to be somewhat economically efficient. The Likert scale enabled the responses to be classified, tabulated and comparisons to be made between the professionals' and parents' views. Some questionnaires returned were incomplete or had partial responses and did influence the total comparisons of the variables presented. The analysis of data was completed based on the total responses of each variable.

POPULATION

The professional population included every Social Work Department in University Affiliated Facilities in the nation, or forty-seven. (The U.A.F. is a nationally directed program which specifically provides a gamut of multidisciplinary services for children with disabilities and their families. Each facility is affiliated with a major university and interfaces with the respective academic and research interests of the academic institution in addition to

the assessment and clinical services provided.) Social Work Departments do intake interviews, make referrals, assess families, and provide therapeutic interventions or other services to them.

The sample of parents was obtained from the Pilot Parents Association in Nebraska. The membership roster of 1979 was used and included not only a variety of family forms but also rural and urban residents. Questionnaires were mailed to seventy-eight families. Five were returned by the postal service. All families had a child with a disability living in the household. Pilot Parents, as a parent support group, is organized to assist newly identified children's parents and others to adjust to coping with a child's disability. A comprehensive parent training program is provided to parent members in how to help other parents. It was assumed for this study that these parents would have adjusted basically positively to their own child's disability, and were through their own crisis experience, 'recovered', and now in a position of strength enabling them to assist and share with other parents their experiences associated with having a disabled child.

DATA ANALYSIS

The questionnaire's responses were ranked according to the degree of significance ascribed to each on the Likert scale. A comparison was made of the total parent responses to those of the professionals. The degree of difference was identified between them. The open-ended comments were reviewed and common reflections or comments noted and discussed. The identifying information of U.A.F. facilities was used to learn specific staffing patterns,

services, and programs of those facilities. Those separate findings are not presented in this discussion.

DATA ANALYSIS AND FINDINGS

The data were obtained from the forty-one questionnaires returned by the parents and seventeen Social Work Departments at University Affiliated Programs. The responses were then totaled for each variable presented in the questionnaire. The percentage of total responses was ranked for both parents and professionals. A table is presented for those variables found by at least sixty percent of the respondents to have a positive impact on the family's adjustment. Table I presents those viewed by parents to be least significant.

TABLE I

<u>Variable</u>	<u>Percent of total responses viewing item as positive factor</u>
1. Parent has a good awareness, knowledge and understanding of the child's condition	93
2. Parents have individual or group opportunity to discuss child with other parents with a disabled child	85
3. The child was infant to two years old at the time of diagnosis of the disability	83
4. The family has secure economic resources	71
5. The family has received counseling services	67
6. The disabled child has siblings	62
7. The family receives ongoing extended family support	60
8. The family has a strong personal faith and religious affiliation	60
9. The family resides in an urban residence	60

TABLE II

<u>Variable</u>	<u>Percent of total re- sponses viewing item as insignificant factor</u>
1. The family is biracial	78
2. The disabled child is a middle child	75
3. The disabled child is an only child	71
4. The disabled child is the oldest child	71
5. One parent also has a disability	71
6. There is more than one child with a disability	69
7. The disabled child is an adopted child	68

Table III reflects those variables in which there was a split of parent opinions so diverse that no consensus was possible in analyzing the degree of influence these factors had upon a family. These illustrate a point well known to professionals who work with families with a disabled child, principally the fact that some factors that appear to have a significant impact upon one family will not necessarily have a similar effect upon another. The assessment of families needs to consider these unique qualities. More ambivalence or uncertainty is also apparent. This is noted in the middle column of Table III, representing the mid-line score (4) of the Likert scale.

TABLE III

Diverse Responses of Parents (Number Indicating
Either Low Degree of Significant, High Degree
of Significance or Uncertainty)

<u>Variable</u>	<u>Low degree of significance (1-3)</u>	<u>Uncertain (4)</u>	<u>High degree of significance (5-7)</u>
1. The household has one unemployed spouse and one employed spouse	39	5	56
2. The disabled child is the youngest child	40	8	52
3. The family has had a previous crisis experience	44	5	51
4. The spouses have been married at least five years before the entry of a disabled child	42	12	45
5. The family is a single parent one	56	5	39
6. The spouses are over 30 at the entry of the disabled child	56	8	36
7. The family is a blended - reconstituted family	53	15	33
8. Family resides in a rural residence	57	15	28

PROFESSIONAL RESPONSES

Table IV presents those variables identified by professional social workers as having a significant impact on the family's positive adjustment to a disabled child.

TABLE IV

<u>Variable</u>	<u>Percent of total re- sponses viewing item as positive factor</u>
1. Parents has a good awareness, know- ledge and understanding of the child's condition	95
2. Parents have individual or group opportunity to discuss their child with other parents	88
3. The family received counseling services	87
4. The child was infant to two years old at the time of diagnosis of disability	78
5. The disabled child has siblings	77
6. The disabled child is adopted	76
7. The family has secure economic resources	76
8. The family has a strong personal faith and religious affiliation	72

The professionals' responses reflected more uncertainty or diverse opinion than the parents' responses, especially when ranking variables on the lower end, or one through four, of the Likert scale. Fewer responses were given to indicate little or no significance and more were given to note an uncertain or no opinion rank such as four on the one-seven scale. Only one variable, the biracial family composition, received seventy percent of the responses, indicating the belief that this factor has little or no significance for the family's positive adjustment. There were no other variables in which there was at least a fifty percent level of agreement.

COMMUNITY SERVICES

Figure 1 indicates those community services viewed as most supportive in providing for the family's and child's needs. The

Respite Care

Church

Physician

Welfare Resources

Neighbors

School Personnel

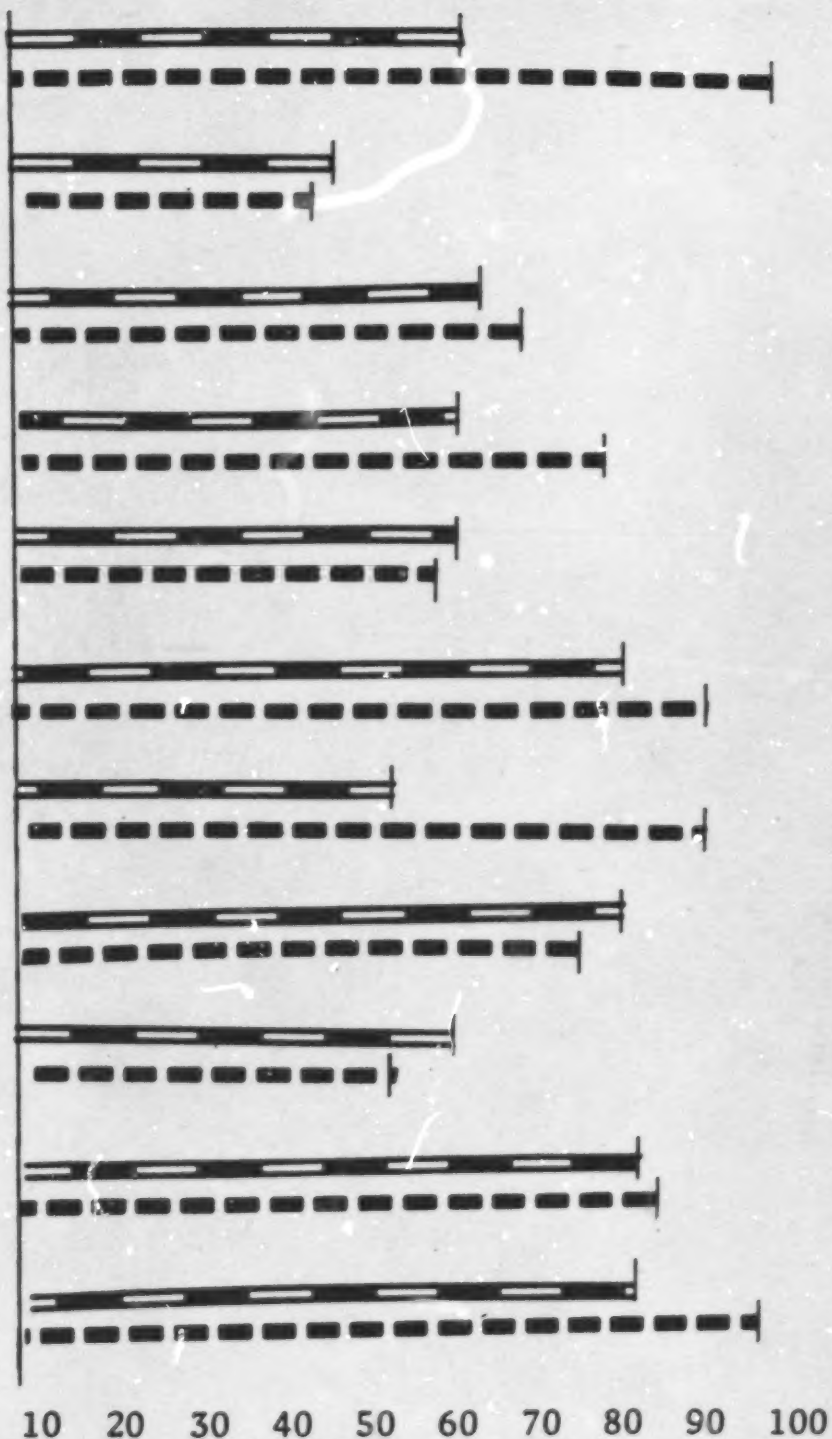
Day Care Facilities

Medical Facilities

Visiting Nurse
Associations

Professional
Services

Community-Based
Special Programs



----- Professional Responses

————— Parent Responses

percentage of responses is indicated for both the parents and the professionals.

DISCUSSION OF FINDINGS

The parent responses generally reflected more opinionated views than those of the professionals. The parent responses were more diverse, indicative either of positive or negative views while professionals tended to express slightly higher levels of agreement on those variables viewed as having a positive influence on families.

There was a high level of agreement between the professionals and parents on those variables viewed as having the greatest amount of impact upon the family's positive adjustment. Both agreed that awareness, knowledge and understanding by the parents of their child's condition was the most important factor in their positive adjustment to it, and influencing the potential of strengthening the family unit. There was a high level of consensus that the earlier this knowledge and diagnostic information was provided, the better it was for the parents. Eighty-three percent of the parents and seventy-eight percent of the professionals believed the potential for adjustment is best if the child's diagnosis occurs between birth and two years of age.

The opportunity to share this experience with others was reported as highly important. Parents identified supportive parent groups, professional counseling, and support from extended family, friends and neighbors all as being helpful to the family. Eighty-eight percent of the professionals agreed parent support groups

were helpful, and professional counseling services were viewed as significant services by eighty-seven percent. The professionals did not rank the extended family supports or neighbors to be as significant as these services.

Both samples believed that having more than one child in the family unit increased the family's potential for a good adjustment to a disabled child. The professionals viewed this as a somewhat more significant factor than did the parents. Nearly three-fourths of the parents did not view either the birth ordinal position or the presence of more than one disabled family member as having any impact upon the family's adjustment. Professionals' views on these factors were not in agreement to the extent that there was not fifty percent agreement. It was especially interesting to note parents did not believe that the age of parents or length of marriage made any difference in the family's adjustment process. More than half reported these factors are unimportant and do not influence the family's adjustment to a disabled child. Parents also reported they do not believe a family who has already undergone a crisis experience together would be more likely to adapt positively to learning of their child's disability (a potential crisis generating situation). These findings tend to contradict other reports, clinical findings and studies. More study and clarification are needed in these areas.

There was also agreement between parents and professionals on the positive influence one's personal faith and religion has as a strengthening factor for the family. The researchers had

speculated this would be a highly important variable. Sixty percent of the parents and seventy-two percent of the professionals agreed. When reviewing the degree of significance of the church as a community resource, however, it was interesting to note both parents and professionals ranked this lower than any of the other resources listed. Is it the parents' personal religious philosophies, beliefs, and the meanings ascribed to having a child with a disability that make one's religious affiliations important? This certainly merits further investigation and has implications for professionals in evaluating and providing cogent services, and in accurately assessing the family's situation.

Current legislative trends providing services for families with a disabled child seem to be moving in a positive direction, according to this survey. Both professionals and parents agreed that having secure economic resources does increase the potential for the disabled child to be accepted and to not be viewed as a potential burden. Supportive resources were identified as important in those community services listed. School, medical, and professional services such as occupational, speech, and physical therapy, were all ranked as highly supportive. Diverse opinions were found between the professional and parent respondents on the benefit of respite care, day care, and welfare resources. It is possible that these discrepancies were reflective of the philosophy of the rural population where these are viewed as less accessible. Community-based programs and services were seen as the most important element by both groups.

The literature, other studies, and professionals discuss what impact the family's structure or form has upon individual family members, and the potential strengthening or destructive influences these can have upon the adjustment to a disabled child. More than half of the parents in this survey did not agree with the basic ideas expressed by professionals. The position of a disabled child in the family, an adopted child, a bi-racial marriage, a single parent family, and a reconstituted family were all viewed as having little or no significance in the family's potential positive adjustment. Parents were split in their opinions concerning the impact of a dual career family. Fifty-six percent believed the family would adjust best if there were one unemployed spouse and one employed spouse.

SUMMARY

The information obtained from this survey identifies some variables considered important in strengthening families with a disabled child. The study concluded that families adjust more positively when they have early awareness, knowledge and understanding of their child's diagnosis, and this experience comes to have meaning for the family members, both individually and as a small group. When parents realize their own and their child's situation realistically, and can mutually progress toward ascribing some meaningful interpretation to the accompanying experiences, they will more readily accept the child's situation and view it as a potentially positive one. The family member's personal faith and the opportunity to share experiences with others appear to

contribute to the resolution, and ultimate positive view of the disability of the child. Supportive groups, professionals, extended family, and friends are viewed as valuable contacts. Families also view the availability of resources and ongoing services to be of important assistance in providing for the disabled child.

These findings have implications for working with such families. The need for accurate diagnosis and information on the child's disability as early as possible is important. The responses of each family member to the child's disability and the impact each has for the present and future functioning of the family unit need to be carefully assessed. Therapeutic interventions that contribute to functional or dysfunctional reactions by each member need to be considered carefully as they influence the family's interactions and group milieu. Prospective new conflicts should be identified, such as a grieving or guilt response in one parent in collusion with an angry or blaming response in another parent. The parents should be referred to and included in the available supportive relationships and resources which serve the child.

Further information and study are certainly needed to learn more about the impact the family's structure has upon the adjustment of a disabled child. The researchers had initially hypothesized that the composition of the family would be a factor influencing the reactions to a disabled child. This survey found that parents did not affirm this belief, and professionals were

generally unsure but tended to agree with the initial hypothesis. Further study is needed to learn if these perceptions are shared by a larger sample population, and what are the reasons or experiences which substantiate the views. What confirms or negates the researchers' belief that there would be significant differences in a single parent residence, in a family with biracial spouses, or when the child is adopted. Similarly, the potential influence of the age of the parents at the time of the occurrence of the child's disability and the length of the spouses' marriage were not viewed as significant by parents. Clinical evidence does not support this view in that those couples who have been married longer generally are able to support, assist, and share with each other in those traditionally established patterns their years of shared life have developed. Single parents, adoption, and the racial composition of couples are known to have an impact on individual adjustments and overall family function. Why parents viewed these as non-contributory factors and why professionals were basically unsure of their views merit further investigation. The population studied, the research design, or other extraneous, uncontrolled variables could have influenced the results, especially since the various family compositions of those respondents were not obtained. This study did provide the basis of information sought to better learn of the general observations of parents and professionals and to learn of further areas for study with more sophisticated empirical methodologies. It contributed relevant information to the initial research question of what factors and services

seem to influence the family's reactions to having a disabled child and how can professionals facilitate their positive adjustment to it.

Notes:

- ¹ Crisis in Child Mental Health: Challenge for the 1970's. Report, New York: Harper and Row, 1970.
- ² Waisbren, S., "Parents' Reaction After the Birth of a Developmentally Disabled Child", American Journal of Mental Deficiency, 1980, Vol. 84, No. 4, 345-351.
- ³ Sieffert, A., Parents' Initial Reactions to Having a Mentally Retarded Child: A Concept and Model for Social Workers, Clinical Social Work Journal, 1978, 6, pp. 33-45.
- ⁴ Trembath, E.J., Angle, C., Stark, J., and Strand, W., "Familial and social acceptance of myelodysplastic-hydrocephalic children." Paper presented at the American Academy of Cerebral Palsy, Los Angeles, California, September, 1976.

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